DOCUMENT RESUME

ED 318 174 EC 230 576

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TITLE Serving Culturally Diverse Families of Infants and Toddlers with Disabilities.
INSTITUTION National Center for Clinical Infant Programs, Washington, DC.
SPONS AGENCY Health Resources and Services Administration (DHHS/PHS), Rockville, MD. Office for Maternal and Child Health Services.
PUB DATE 89
GRANT MCJ-113271
NOTE 31p.
PUB TYPE Collected Works - Conference Proceedings (021) -- Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS Cultural Awareness; *Cultural Differences; *Delivery Systems; *Disabilities; *Early Intervention; Family Involvement; Infants; Preschool Education; Program Development; State Programs; Toddlers

ABSTRACT

This publication emerged from an invitational meeting held by "Project Zero to Three" to address how best to provide effective, culturally sensitive, and comprehensive early intervention programs to all infants and toddlers with disabilities and their families in an equitable way. Following an overview of the concept of culture and how that concept may be understood and used by human service providers, specific cultural issues are discussed, such as family definitions, roles, relationships, and child-rearing techniques; health, illness, and disability beliefs and traditions; and communication and interactional styles. This information is then used as a basis for suggesting strategies which states might consider in their efforts to enhance cultural sensitivity in services. The strategies focus on data collection, family participation in policy making and program design, public awareness, working with individual families, staffing, monitoring, and evaluation. Included are a list of 22 references, a list of 33 recommended readings, and descriptions of resource organizations and projects. (JDD)

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Serving Culturally Diverse Families of Infants and Toddlers with Disabilities

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Serving Culturally Diverse Families of Infants and Toddlers with Disabilities

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National Center for Clinical Infant Programs
1989

The National Center for Clinical Infant Programs is a non-profit, tax exempt corporation. It was established in 1977 by outstanding representatives from the fields of mental health, pediatrics, child development, and related fields, as well as community leaders, in order to improve and support professional initiatives in infant health, mental health and development. We hope that this publication will add to the information base of those who seek to improve services for all infants and toddlers with disabilities and at risk of disabilities and their families.

This publication was supported by project #MCJ-113271 from the Maternal and Child Health program (title V, Social Security Act), Health Resources and Services Administration, Department of Health and Human Services.

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Foreword

From 1983 until 1989, under a grant from the Bureau of Maternal and Child Health and Resource Development, U.S. Department of Health and Human Services, the National Center for Clinical Infant Programs (NCCIP) provided technical assistance and served as a forum for information and resource exchange to fifteen states working to develop comprehensive and coordinated early intervention services for infants and toddlers with disabilities and their families. The fifteen states included in this "Project Zero to Three" were: Florida, Hawaii, Iowa, Kansas, Maine, Maryland, Massachusetts, New Jersey, New York, North Carolina, Ohio, Oregon, Texas, Utah, and Washington.

"Project Zero to Three" was guided by a Core Advisory Panel which included several members of NCCIP's Board of Directors, representatives of federal agencies, individuals with experience directing national projects and providing clinical services, and parents of young children with disabilities. Each year the Core Advisory Panel, "Project Zero to Three" state representatives, and resource persons with expertise in relevant areas attended a national meeting to share and review their experiences and to identify service gaps and theoretical issues yet to be addressed. The Project also brought together parent representatives from each state so that they, too, could share their experiences, identify and begin to address unmet needs, network with parents from other states, and keep abreast of relevant state and federal activities.

Further, small invitational meetings were held periodically to provide the states with an opportunity to address specific areas of concern. Topical publications frequently were generated as a result of these meetings. This publication emerged from such a gathering. In response to concerns expressed by state representatives an invitational meeting was held in April, 1988, which addressed the issue of how best to provide effective, culturally sensitive and comprehensive early intervention programs to *all* infants and toddlers with disabilities and their families in an equitable way.

We extend special thanks to those who assisted us in planning for the meeting on "Serving Culturally Diverse Populations of Infants and Toddlers with Disabilities

and their Families"—Aaron Favors, Ph.D., Director, MCH Program Coordination and Systems Development Branch, Office of Maternal and Child Health, Bureau of Maternal and Child Health and Resource Development, U.S. Department of Health and Human Services; Jane Lin-Fu, M.D., Chief, Genetics Services Branch, Division of Services for Children with Special Health Needs, Office of Maternal and Child Health; and Mary Thorngren of the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO) in Washington, D.C.

Special appreciation is due again to Dr. Favors for introducing the meeting, and to our speakers, Dr. Lorraine Cole, American Speech, Language and Hearing Association in Rockville, Maryland; Dr. Richard Roberts, with the Center for Development of Early Education in Honolulu, Hawaii, at the time of meeting (and now with Family Based Education Centers at Utah State University in Logan, Utah); and Sister JoEllen Shannon, East Coast Migrant Head Start Project in Arlington, Virginia.

We also thank those participants whose expertise in facilitating four issue-specific work groups was invaluable to the success of the meeting and thus to the development of this publication—Joyce Lindgren and Andrea Calloway, Co-facilitators, Parent Participation Work Group; Emily Vargas Adams and Jane Lin-Fu, Co-facilitators, Cultural Perspectives Work Group; Randi Malach, Facilitator, Assessment Issues Work Group; and Richard Roberts and Elizabeth Uchytil, Co-facilitators, Outreach Work Group.

Finally, we extend our thanks for continuing support and assistance in all aspects of "Project Zero to Three" to Diana Denboba, Project Director in the Office of Maternal and Child Health during the Project's final year; Kathleen Kirk Bishop, D.S.W., Project Director for "Project Zero to Three" at the time of the meeting; Merle McPherson, M.D., Director of the Division of Services for Children with Special Health Needs, Office of Maternal and Child Health; and Vince Hutchins, M.D., Associate Director for the Office of Maternal and Child Health, Bureau of Maternal and Child Health and Resources Development.

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Introduction

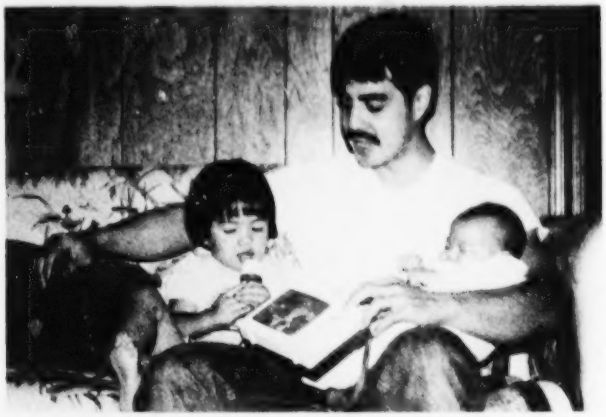
"Culture," according to anthropologist John Obgu, "shapes the way of life *shared* by members of a population. It is the sociocultural adaptation or design for living that people have worked out [and continue to work out] in the course of their history" (Ogbu 1987: 156, emphasis supplied). As cultures vary, so do notions of what the human body symbolizes, how it should appear, how it functions most appropriately and why, when and how it should be treated. Conditions which are viewed as physical, mental or emotional impairments, as well as appropriate responses to such conditions, vary from culture to culture.

There are cultural and situational influences which, if ignored, may, from the outset, doom to failure even the best intentioned programs for culturally diverse infants and toddlers with disabilities and their families. Cultural variables include, for example, how people feel about, manifest and treat health, illness, and physical, mental, and emotional disabilities; the group of people in one's life who are considered to be family members and the relationships these people have to each other; childrearing techniques; and language and the different ways in which people communicate. It is important to remember that situational and environmental conditions such as poverty, homelessness, lack of formal education, and other factors that put children and families at grave risk are *not* cultural attributes. These conditions are variables which cut across *all* cultures.

This publication is designed to assist policymakers and practitioners in their efforts to develop programs and serve families with infants and toddlers with disabilities within the families' own cultural frameworks and individual lifestyles. The ideas and suggestions in this publication reflect the available, but scant, literature on cultures and disability; background papers by Alicia Lieberman on cultural sensitivity and by Penny Anderson on culture and disability; personal communications from members of a variety of cultures and from practitioners who work in various capacities with members of diverse cultures; and the professional and parent participants in NCCIP's Spring, 1988, meeting on serving culturally diverse populations of infants and toddlers with disabilities and their families.

Following an overview of the concept of culture and how that concept may be understood and used by human service providers, some of the specific cultural issues noted above are discussed—family definitions, roles, relationships and childrearing techniques; health, illness, and disability beliefs and traditions; and communication and interactional styles. This information is then used as a basis for suggesting strategies which states might consider in their efforts to enhance cultural sensitivity in services to young children with disabilities and their families.

Information about cultural clusters and any specific cultures, as well as anecdotal materials are provided as examples only. They must not be construed as automatically applying to *all* families within a particular culture.



Serving Culturally Diverse Families of Infants and Toddlers with Disabilities

Culture—The All-Encompassing Variable

Culture can be conceptualized as the specific framework of meanings within which a population, individually and as a group, shapes its lifeways. A cultural framework is neither static nor absolute. It is, in a sense, an ongoing process, within which individuals are constantly reworking or trying out new ideas and behaviors.

The cultural framework must be viewed as a set of tendencies of possibilities from which to choose. To ascribe to culture a more deterministic role in the lives of individuals or families results in stereotyping, and stereotyping creates barriers to understanding which are as impenetrable as those created by cultural ignorance. For example, there exists no generic entity which may be dubbed *"the* Southeast Asian family," *"the* Native American family," or *"the* European American family." Each of these categories encompasses numerous cultures; their individual members may share tendencies in some areas and not in others. And further, there is no entity which can with authority be called *"the* Vietnamese family," *the* Navajo family," or *"the* Italian family." Individuals and families will be found to lie along different points of their cultural continuums (from traditional, for example, to fully bicultural). It cannot be expected that each family and individual within a culture will respond in the same way to the same or similar situations. While this publication is broadly focused on "Asian Americans," "Hispanic Americans," "African Americans," and "Native Americans," these are valid cultural distinctions only in the very broadest sense of the term.*

Thus, cultural sensitivity cannot mean knowing everything there is to know about every culture that is represented in a population to be served. At its most basic level, cultural sensitivity implies, rather, knowledge that cultural differences as well as similarities exist, along with a refusal to assign values such as better or worse, more or less intelligent, right or wrong to cultural differences; they are simply differences. For those involved in early intervention, cultural sensitivity

further means being aware of the cultures represented in one's state or region, learning about some of the general parameters of those cultures, and realizing that cultural diversity will affect families' participation in intervention programs. Cultural knowledge helps a professional to be aware of possibilities and to be ready to respond appropriately.

It is important for professionals to let family members take the lead in revealing their own place within their cultural paradigm. Thus, if a professional knows that members of some cultures avoid eye contact out of respect, she or he will not assume that avoidance of eye contact indicates shyness, ambivalence, shiftiness, embarrassment, guilt, or any other "mainstream" associations connected with aversion to "looking someone in the eye." Such an assumption would be ascribing a value based upon a professional's own culture, rather than based within the context of any other group. But neither will a culturally sensitive professional assume that all individuals in a culture whose members tend to avoid eye contact will in fact do so. Rather she or he will be aware of the possibility, but will take the lead of the individuals being served, who either will or will not maintain eye contact or will fall somewhere in between.

Family and Childrearing, Culturally Defined

The concept of what constitutes a family differs from culture to culture, although all cultures distinguish between people who are "related" to each other and those who are not. The structures of families may vary a great deal between cultures, as may relationships expected between family members.

In many cultures, the family is "extended" in various ways. Numerous relatives and frequently non-relatives (by mainstream definition) or temporary relatives may comprise the primary closely knit group. The family may be for the most part constant, with its changes occurring consistently through the life events of birth, marriage and death; or it may be somewhat fluid. For example, distant kin or non-kin who are nevertheless considered to be family members may be more or less a part of the extended family household as situations and relationships with core members fluctuate. The extended family may be a person's most important support network, and individuals may also be expected to make personal sacrifices for the sake of the extended family. Individuals within diverse family structures have varying roles vis-a-vis each other, and these roles and relationships may change over time. For example, a family may have some form of strict hierarchy, with or without rigidly defined gender roles, or may be totally or relatively egalitarian in terms of some or all of its members.

Ideas about the process of childrearing are also culturally defined. Children are raised in a way that socializes them "for optimal adjustment and success in their home culture" (Westby 1986: 13). Members of different cultures vary in their ideas about who cares for and educates children of differing ages and sexes, the expectations of children at different stages of development, and the kinds of competence and behaviors seen as normal or ideal. Child development researchers have focused their attention on middle class mainstream children and their mothers (Westby 1986), but children in many cultures may be cared for to a significant extent by their mothers and also by siblings, grandparents, other relatives, neighbors, entire families or even entire communities.

If cultural norms or ideals require that children become competent in areas other than those needed in the social mainstream, childrearing methods and outcomes may vary as well (Ogbu 1987). Practices that seem incomprehensible to uninformed persons from other cultures may make perfect sense in the context of the culture itself. Stack (1974) notes, for example, that, contrary to the impression frequently left by studies of poor African American families, their system of shared childcare and parenting arrangements is not indicative of disorganized, haphazard, uncaring or broken family life. This kinship interaction, which intertwines a system of life-sustaining exchanges of goods and services, in fact reflects a creative form of adaptation to poverty which enables those concerned to survive under extremely difficult circumstances. But it is not a phenomenon restricted to poor African American families. While the constant exchange found among extremely poor African American families may lessen as families climb the socioeconomic ladder, McAdoo (1979) and others have found that members of the African American middle class do tend to maintain mutually supporting family and kin networks. This makes such support appear to be a cultural tendency rather than strictly an adaptation to poverty.

*What is considered appropriate terminology for members of these broad cultural groupings varies among individuals and groups and changes over time as well. The above terminology is based upon current literature, advice, and an attempt to be consistent across cultures. "American" is used in this publication only to refer to persons in the United States, recognizing that there are other "Americans" as well, and, further, that not all of the people residing in the United States within these groupings consider themselves to be "Americans" as the term is used in this publication.

Some examples of family structures and childrearing tendencies in different cultural groups suggest both the variety of patterns and their internal cohesiveness. Again, the reader is cautioned to use these examples as a guide to inquiry only. Cultural frameworks suggest important tendencies and possibilities; an individual or family's unique characteristics and experiences must also be understood.

Examples of Family and Childrearing Tendencies in Different Cultural Groups

- An **Asian American** family may function via a strict gender, sibling, and age hierarchy. In this hierarchy, fathers may hold a traditional leadership role, with mothers functioning as family nurturers and caretakers, in submission to their husbands, with their younger male children submissive to older male children, and female children submissive to all. Traditional Asian families tend to be extended, with families very close and with many generations often living under one roof. Children may be strictly controlled and physically punished. Asian American parents generally take very active roles in augmenting and encouraging their children's learning activities at home (Lin-Fu 1989). However, where language and cultural barriers are in place, family members may be reluctant to attend PTA and other school functions.
- An **African American** family may also be extended, with loyalty to the extended family encouraged in addition to independence and assertiveness. Mothers and grandmothers are traditionally central influences on young children, but the current prevalence of female headed households has raised serious concerns among African Americans about how to support father/child relationships. Children tend to be the focus of African American families. While infants are nurtured warmly and affectionately, concern about "spoiling" babies may also be expressed. African American families have a strong belief in disciplining inappropriate behavior in children. The discipline administered may range from an "evil eye" (which conveys to the child that it is time to stop a behavior immediately), to threatening to punish, to "spanking" (Anglo terminology) or "beating" (African American terminology) (Strickland 1989).
- Members of **Hispanic American** families may also identify themselves first and primarily as members of their extended families. In patriarchal Hispanic families, the attitude of *machismo* may be an important force. In an Hispanic American family *machismo* tends to refer to a husband/father's ultimate responsibility for the care and well-being of his family, without the negative connotations the term has taken on elsewhere. Thus, it may be appropriate for a husband to make decisions without consulting his wife, although a woman may be expected to consult with her husband and other family members before making similar decisions. Children may be expected shortly after marriage, with pregnancy and childbirth often seen as natural events needing no medical supervision or intervention under ordinary circumstances. Infants tend to be the center of uncritical attention, but toddlers are expected to begin to learn acceptable behavior.
- In **Native American** cultures, the extended family may also be the primary source of support and identity. In a number of tribal cultures, grandparents and elders traditionally exert a powerful influence over their adult children and the raising of grandchildren. Traditional families may also designate a member to serve as spokesperson for their group to outsiders. All family members are likely to help with childrearing. Native American children tend to be treated with respect for their innate characteristics, which are believed to be permanent; there is tolerance for mistakes, with censure and punishment minimal.

Health, Illness, and Disability: Beliefs and Practices

Culture shapes beliefs and practices concerning health, disease, and disability. Our basic definitions of disabilities are cultural constructs, as are the deeper meanings we assign to disabilities. Responses to disabilities and to people with disabilities are culturally shaped as well. Some people with specific disabilities consider themselves to be members of a culture by virtue of their disability (although within the group the disability is not viewed as such). This is especially true, for example, of many persons with severe hearing impairments or deafness. As always, variations in beliefs and behaviors are found both within and between cultures.

Examples of health, illness and disability belief and practice tendencies in different cultural groups

- While little has been written about concepts surrounding disabilities and handicapping conditions among **Asian American** populations, Nguyen (1987) reports that birth defects and other disabilities may be viewed as punishments for sins committed not only by parents but by more remote ancestors as well. The families of infants born with disabilities may resist initial intervention efforts; in Buddhist families, for example, if such a child should die, she or he may be reincarnated in a more "whole" form (Biro 1989).

It may also be believed that unborn children can be harmed if a pregnant woman fails to avoid places and situations where evil spirits may be lurking. To the extent that a child's defect may represent a punishment, the child may be isolated from society and considered an object of shame for his or her family.

- Little, if anything, has been written about **African American** families in terms of disabilities and handicapping conditions. There have been efforts, however, to look at the general health and illness behaviors of this population in cultural terms. Bailey, for example, notes that health education programs will more closely match the needs and gain the attention of African Americans if such cultural traits as "sharing, strong emphasis on family bonding and childrearing, a strong authority structure, the importance of spiritualism, an emphasis on present orientation, trust, and individual moral 'strength'" are recognized and incorporated (1987: 390).

- **Hispanic American** families tend to prize vitality and health and may place the responsibility for care on the entire family. Thus, including the family is often essential in both health service provision and in preventive education (National Coalition of Hispanic Health and Human Services Organizations 1988).

In families where health and vitality are especially valued, an infant or a child with a disability may be hidden and thereby deprived of treatment. Hispanic American beliefs surrounding disability may be strongly intertwined with religion, within which a child's disability may be perceived as punishment for a parent's wrongdoing. Samora (1978), for example, notes the belief that making unfounded accusations about another may cause one's own child to be born with physical disabilities. On the other hand, however, malevolent forces may cause severe or chronic health problems for no reason at all. The innocent victims of such treatment may be passive and indulged by family members and friends. The victim may fully expect to be cared for

without having to participate actively in her or his own care at all (National Coalition of Hispanic Health and Human Services Organizations 1988).

- In most **Native American** cultures, health and religious beliefs are intertwined, with parental behavior often seen as causally linked to birth defects or disease. Among the Hopi, a pregnant woman who breaks a taboo against cruelty to animals, marrying into her own clan, adultery, quarreling, fishing and/or swimming may not be living the "Hopi Way" and thus may lose spiritual protection for her fetus. Pregnant Crow women are discouraged from looking at anything deformed or at a corpse, lest the vision "show up" on the child (Farris 1978: 28).

As noted, different disabilities may cause different levels of concern in different cultures. For example, congenital hip dislocation, common among Navajos, has traditionally been viewed as little cause for concern. But because epilepsy has traditionally been seen as originating in sibling incest, this condition may be regarded with great dismay. Traditional Navajos may tend to isolate their children with epilepsy, whether or not medication is used. Less traditional Navajos tend to use medication to control their child's epilepsy in order that the child may be able to participate more fully in community life (*see*, for example, Kunitz 1983).

Attitudes surrounding disabilities in general, as well as specific conditions, change over time. Locust (1986), for example, reports that traditionally the Hopi have integrated people with handicaps into their society, with responsibilities commensurate with their abilities. However, exposure to mainstream culture has brought with it exposure to the stigmas that may be attached to disabilities.

Family/Professional Interaction

An infant or toddler with a disability can create stress in any family. If professionals wish to alleviate rather than exacerbate that stress, they need to understand how help may be sought and used in a culture, the patterns of communication between family members and others, and families' perceptions of professionals.

Practitioners and program developers concerned with infants and toddlers with or at risk of developing disabilities would do well to remember how difficult "early intervention" can be to explain even to mainstream professionals and parents. Specialized healers and teachers can be found in most cultures. But in many cultures it is members of the extended family who are "case managers" or "home visitors" who give childrearing advice. Would-be helpers need to remember that members of a family who have limited familiarity with a professional's ordinary English may be utterly confused by professional jargon. If family caregivers do not understand what is being asked of them or their child, professional "help" can be damaging rather than beneficial. Family members must not be put into a position of choosing between traditional healing and helping practices and mainstream programs which they may or may not understand, agree with or value. Rather, efforts should be made to integrate mainstream and traditional approaches when a family so desires.

Communication

Communication is the essence of parent/professional interaction. Spoken language, body language, and other forms of communication have important—and varying—cultural meanings.

Members of some cultures simply will not go to facilities unless a number of speakers of their own language can be found there. Ideally, service providers will understand and be articulate in a client's culture and language (including the languages of sign). When use of interpreters is unavoidable, it is essential that they are well-trained, skilled professionals who are able to make conceptual transfers, including transfers of idiomatic usages and meanings of intonation, and not just literal translations of spoken or signed words. Especially in a clinical setting an interpreter must know the technical concepts involved in both languages, and must be able to change them into terms that both the client and the professional will understand.

Body language and other forms of communication are important considerations in addition to spoken or signed languages. Members of different cultures may, for example, have varying concepts of "personal space," preferring to sit or stand closer to or farther from others than a professional is accustomed to doing. Members of different cultures have different ideas about the meaning of direct eye contact; in some cultures prolonged eye contact may be a sign of disrespect. Touching has different meanings in different cultures as well. In some, to touch a client may be offensive, especially a client of the opposite sex. In other, for example Hispanic, cultures touch may be a common form of non-verbal communication.

Varying cultural concepts of time can present major barriers to effective parent/professional interaction and collaboration if not understood or respected. Heavily scheduled mainstream professionals may see lack of "punctuality" as evidence of hostility or backwardness in people for whom the notion of punctuality itself may have a cultural meaning quite different from that of a professional. The same professional, on the other hand, may expect family members to share intimate feelings on the briefest of acquaintance, while for members of the family's culture trust is something to be established slowly.

Examples of communication and interactional tendencies in different cultural groups

- Many **Southeast Asian** families refuse to visit facilities in which they have experienced, or have heard from others that they will likely experience, discriminatory and disrespectful treatment by *any* person, including reception staff (Nguyen 1987). This underscores the need to educate *all* staff members in cultural awareness and sensitivity.

Respect for authority and for age in Asian cultures should be given consideration in provider/client interaction. Asking questions of persons in authority (e.g., health care providers) may be considered disrespectful, and patients who do not fully understand instructions may not ask for clarification. Health professionals should be sensitive to the fact that patients and clients who are older expect to be treated with respect. For example, in addressing an extended family, the oldest member should be addressed first. That person may, in fact, hold the key decision-making position in the family (Lin-Fu 1989).

Asian American families may also see dress as reflecting the degree of respect accorded one person by another. Thus a home visitor who dresses casually, either thinking to put a family at ease or simply because she or he will be sitting on the floor with a toddler, may be perceived by family members as showing contempt or lack of respect. Direct eye contact may be considered extremely rude. An Indochinese American client's response of 'yes' to a suggestion, idea or program outline may actually mean simply, "Yes, I heard you"—

Indochinese more likely say 'Yes, I agree,' if they do in fact agree (Texas Department of Human Services).

- **African American** families have experienced discrimination and disrespect in numerous forms, many of which hearken back to the treatment of African Americans as slaves. Even today, an African American may be denied the overt symbol of respect conveyed by being addressed by his or her appropriate title—Ms., Mr., Mrs., Miss, or Dr. African American social workers have also noted that mainstream professionals often have inappropriately low expectations for African Americans as clients or students (Jenkins, 1981)—a covert but serious barrier to full communication. Blendon et al. (1989), reporting on a 1986 survey comparing Black and white access to and use of health care, found that while the financial circumstances and under- or uninsured status of many Black Americans makes them less likely to have access to health care services than whites, even Black Americans above the poverty line were found to have less access to health care than their white counterparts, with "the care provided differ[ing] for blacks and whites along a number of dimensions" (1989: 280). Longer waits (over a half hour) to see physicians were reported by Blacks than were reported by whites. In general the study found Black Americans less satisfied than whites with the health care they received.

- **Hispanic American** clients may be more present oriented than the potentially more future oriented mainstream professional, and may be impatient with attempts at long-term planning (Kunce 1983). This is certainly true if the planning is done *for* them rather than *with* their consent and agreement. In working with any culture, professionals must remain cognizant of the fact that long-term planning must be carried out in partnership with the family (Strickland 1989).

  Establishment of a personal relationship may be vital to serving a Hispanic American family, necessitating devotion of considerable time to establishing an atmosphere of trust and openness (Lieberman 1987). Many Hispanic Americans will expect health providers to "be warm, friendly, and personal—to take an active role in the patient's life" (National Coalition of Hispanic Health and Human Services Organizations 1988: 74), and will expect to establish and maintain a relationship with specific providers, not providers' institutions. At the same time, however, until an individual indicates that less formal communication is appropriate, use of formal titles with Hispanic American adults is extremely important as an indication of respect.

- **Native American** parents tend to judge professionals slowly. As a Navajo tribal chairperson has put it, "We Navajos will look you over for a couple of years, and then decide if we are for you or against you" (*in* Polacca 1966:1). If service program staff change frequently, no one may be able to establish enough trust to work effectively with families. Time can be an issue even when trust has been established. Because parents from many Southwest Native American cultures have been taught to respect and defer to the perceived needs of people in authority, they may not discuss their concerns if they feel that a doctor or educator is in a hurry. Professionals therefore may need to be sure to plan enough time with Native American families so that family members do not feel rushed and will feel free to voice their concerns (Education for Parents of Indian Children with Special Needs [EPICS] 1989).

State Strategies to Increase Cultural Sensitivity

Working within and respecting a family and community's cultural paradigm may mean the difference between successful and unsuccessful early intervention programs. Several overarching principles offer useful guidelines for more specific strategies. Both principles and strategies emerged from the NCCIP Multicultural Meeting held in April, 1988; from the background papers prepared for the meeting; from the literature; from panels and workshops whose participants addressed issues of cultural sensitivity; and from the experience and background of NCCIP staff.

- Recognition and understanding of cultural paradigms is vitally important. At the same time, these paradigms must be viewed as broadly comprised of cultural tendencies which individual families may accept, deny, modify, or exhibit situationally. Attempting to force a family or an individual to fit within any preconceived cultural model is *not* cultural sensitivity—it is stereotyping, and stereotyping must be conscientiously avoided.

- The principle that parents are the constants in their children's lives and the chief decisionmakers about all aspects of childrearing may need to be expanded so that all relevant family members (culturally defined) are considered and encouraged to be full partners in the early intervention process when primary caregivers so desire. Families should be recognized as the source of relevant and unique perspectives and insights regarding their own children and their cultures.

- Cultural errors will be less alienating if clients know that professionals, paraprofessionals, other staff members, and volunteers are committed and sincere in their efforts to provide services to them in a culturally acceptable and appropriate manner. A professional should demonstrate that she or he is willing, indeed anxious, to learn from the family and community as much as he or she is willing to give of professional expertise.

The specific strategies described below are likely themselves to increase the appropriateness of efforts to serve culturally diverse families whose infants and toddlers have disabilities. Consideration and/or implementation of these strategies may also stimulate the commitment to provide additional creative state responses to the challenge of serving children and families from culturally diverse backgrounds.

A Commitment to Serve All Children

A state can demonstrate its commitment to a service system that will reach *all* of its infants and toddlers with disabilities and their families by developing, circulating, and publicizing a statement of that commitment. This effort may help to establish credibility with populations traditionally under- or unserved in many maternal and child health/children with special health needs service areas. The statement of intent or commitment should be printed in all state-relevant languages, and should be disseminated through foreign language newspapers, television and radio stations and other media. Small language groups should not be ignored, since they may be the least likely ultimately to be aware of services.

Data Collection

In order to serve all infants and toddlers with disabilities in a state, planners need to know

- the names and geographic locations of families who may need services and their race and ethnicity, including what specific cultures are represented (not simply "Hispanic," "Native American," etc.);

- the types and severity of disabilities the children have, as well as health needs documented as putting children at risk for disabilities which may be prevalent in certain cultural groups (in order that prevention activities may be considered);

- what cultural tendencies surrounding disabilities, childrearing, family roles and relationships, and communication styles may be in place; and

- what situational variables, such as socioeconomic status, geographic location and resultant resource availability, and residential stability must be taken into account.

This kind of information gathering requires both professionals trained in statistical and survey data collection and professionals trained in applied ethnographic fieldwork in the various settings to be studied. Statistical and ethnographic studies should cover all cultural populations, including all Anglo populations, focusing on the issues noted above—family roles and relationships, childrearing methods, communication styles, manner of accessing the health care system, and cultural beliefs and tendencies surrounding disabilities and chronic illnesses. Relevant state agencies, service facilities (including hospitals), and other resources should be covered in the data collection process as well. Once gathered, such information can be meshed to form a fairly complete picture, in terms of the issues to be addressed, of the various populations and differently comprised and functioning administrations and agencies in the state, all of which will be working together to achieve best outcomes for

infants and toddlers with disabilities and their families. The goal is to paint as broad a picture as possible and necessary of who and what might be involved in developing, implementing, and accessing a culturally sensitive program or system of services. One-time assessments, no matter how extensive, are of limited usefulness; data collection should be ongoing so that programs are kept up to date and in touch with cultural shifts and tendencies within the state. In addition to assessing aspects of cultural diversity and the need for services, states should identify and compile information about existing cost-effective and culturally derived program models.

Family Participation in Policy Making and Program Design

Policy statements regarding the importance of family participation in policy making and program design surrounding early intervention programs should be explicit, including the statement that this participation must include the active involvement of caregivers from the diversity of cultures served. There should be ample opportunities and support for families from these cultures to become meaningfully involved in planning, decision making and implementation in all areas at both the state and local levels—for example as members of Boards of Directors, P.L. 99-457 Interagency Coordinating Councils and other advisory committees; as staff and volunteer trainers, including participating in curriculum development; as staff, volunteers, data collectors and analysts; and as program evaluators. To ensure that such opportunities are available the proportion of such positions which are held by caregivers of children with disabilities, and whether these caregivers reflect the cultural diversity of the state/community should be scrutinized. To be effective, family and cultural representatives in these positions must have the authority to represent the various bodies in which they play a role in order that they may meaningfully participate in a variety of policy-making settings. Specific strategies should be developed to assist family members of diverse cultures in their efforts to carry out their roles in state planning and program implementation by providing, for example, flexible meeting times and locations, training based on needs indicated by families, financial reimbursement (travel, per diem, childcare, free parking, other perks). Finally, recommendations should be actively sought from client families about ways in which they might better be served.

Public Awareness

An extensive and creative public awarenesss program should be developed to assure that as many families as possible who are in need of services will know of their availability. Public awareness efforts should

- clearly define target populations (both by race and ethnicity, disability and culture); and
- develop contacts with community groups, community leaders, members of families with children with disabilities, and adults with disabilities in order to plan appropriate outreach and establish networks for communication and problem solving.

Publicity about screening, assessment. and early intervention services should be developed in all relevant languages, with input from members of each culture and language group represented in the state in order to be appropriate for each one. All materials should be reviewed for cultural appropriateness in terms of content, language, and artwork. Where members of the community have agreed and have been trained to serve as points of initial client contact, their phone number(s) and address(es) should be prominently displayed on publicity materials for the various cultures. Where this has not occurred, a number and address should be displayed from which first time clients can obtain a referral to community contacts who may serve as their first links with an early intervention system.

Materials should stress in a clear and straightforward way any special services which may ease entrance into the early intervention process, e.g., the availability of trained interpreters, childcare assistance in various forms, transportation, flexibility in service locations and hours, and so forth. Written informational materials should be posted and/or distributed wherever they might be seen by parents, other family members, or friends of families with an infant or toddler with special needs. Such places might include health facilities (e.g., hospitals, physicians' offices, clinics, group health offices); public facilities (community centers, libraries); local businesses (grocery stores, drugstores, laundromats); settings where children are cared for (childcare centers, preschools, Head Start programs, family daycare homes, schools); and places of worship. Other informational outlets include local newspapers, newsletters and other publications, including ethnic publications.

Another extremely important source of information exchange is word of mouth. Limited literacy may make it difficult or impossible for some family members to take advantage of materials written in any language. Further, there is a strong oral tradition with some cultures, which makes oral communication a more

culturally appropriate and effective means of informing families about existing services. Forums may include advocacy groups, Native American Tribal Councils, shelters for abused or homeless women and children, hotlines, warmlines (informal, informational/counseling services), and PTA meetings, through all of which referrals might be made based on the information received. Public service announcements can be aired on foreign language radio and television stations. Announcements may be made in places of worship and other community forums, Culturally appropriate videotapes using native speakers may be effective as well.

Working with Individual Families

As noted, it is vital to remember that ultimately services are being provided to *individual* families, and that family service plans must address each family's cultural and situational goals, which include their aspirations for themselves and their child(ren).

Establishing Rapport for Planning

The first priority in working with a family with a young child with a disability is to reach and establish rapport and trust with that family. Previously gathered ethnographic information, as well as the current literature, should provide insights into how this might best be achieved.

Personnel then must determine

- *Position on cultural continuum:* Where does an individual family lie along its cultural continuum, including, for example, how is the family organized (extended or nuclear)? Who are the primary caregivers? What is the family pattern of decision making? What language is spoken at home? Does the family wish to include traditional practitioners or other members of the community in program planning and/or implementation?
- *Values:* What values are shared with the Anglo mainstream? What aspects of working with the Anglo mainstream may be difficult?
- *Comfortable ways of working:* What is the most comfortable way for the family to work with the service provision "system"? and
- *Additional information:* Is there any other information which is important for personnel to know regarding the individual family and child and/or that is important to the family to relate or to question?

Every attempt should be made fully to involve every family in the development of its own service plan, recognizing, however, that some (or even all) services may be unwelcome in some families or that it may take time for services and service personnel to be accepted. Some services or interventions may be perceived as creating more culturally related difficulties than a child's disability itself. Professionals must be flexible and must be able to consider the interplay of the biases and desires of everyone involved. They must be willing to rethink their professional positions and the types of intervention which they may strongly believe are necessary, as well as their means of relating this information to a family.

Assessment

Developmental assessment must be viewed as an ongoing process that is an integral part of the family service program which recognizes changes in the child and family. The first steps in the assessment process are: determining the family's priorities and the information the family wants to have about its child; determining the aspects of their family life which the family finds relevant to their child's development; and determining what language(s) should be used throughout the assessment process. Only then can the focus encompass actual characteristics of the child and diagnostic concerns (Johnson et al. 1989: 33). Family values and decisions must be respected.

The assessment process should encourage the use of a variety of tools and procedures, including behavioral observation and interviews. Adaptability to cultural diversity should be used as one criterion for choosing assessment instruments or tools. Assessment materials should be carefully scrutinized by culturally aware professionals, family members, community leaders, and other relevant persons to ensure that they are free from ethnocentric bias. When deemed necessary, assessment tools should be reworked to ensure their cultural validity. Families are likely to be able to provide more complete and accurate data for some portions of an evaluation better than that which is derived via a formal evaluation instrument.

Examiners must be sensitive to and knowledgeable about the cultures of the children being assessed, and ideally will be members of the children's cultures themselves. At the very least, there should be on the assessment team a person who is bicultural/bilingual and is a *trained, experienced, and skilled interpreter,* able to converse with the child (depending upon the child's age) and relate to the child and the family in their own language. This person must be able to interpret assessment issues accurately to both family and professionals and to appropriately convey referral information and explanations to the family in a clear, non-threatening and respectful way. Follow-through on

referrals should be carried out in the same manner.

The state should develop a plan to coordinate existing financial resources and to allocate additional financial resources to support a culturally sensitive child developmental assessment and referral process. In the long run, this should save considerable time and expense by reducing the likelihood of implementing inadequate or unacceptable assessment procedures with equally unacceptable or incomprehensible outcomes in some families in cultures other than the Anglo mainstream.

Staffing

All personnel involved in the planning, administration or provision of early intervention services for culturally diverse infants and toddlers with disabilities and their families need cultural sensitivity training. Pre-service training in cultural sensitivity should be actively promoted in colleges and universities, and in-service training for all staff not previously trained should be required (with plans in place for training new staff as they arrive). Staff in-service training should include opportunities to attend relevant seminars and workshops which will continue their cultural sensitivity and knowledge training. Monolingual staff should also be encouraged (and perhaps provided with incentives such as tuition assistance and/or time off) to learn a second language.

In-service staff training and development programs can include written, visual, and oral materials and techniques. Members of a state's cultural communities, including parents or other family members with children with disabilities, community leaders and adults with disabilities, should play a major role in the development of training materials and in actual training. Training sessions may be designed to

- increase staff awareness of the importance of cultural sensitivity in working with families of cultures different from their own;
- present cultural information collected about the populations in the state as well as descriptions of model programs and other helpful resources (with stress on the importance of stereotype avoidance and respect of family individuality within cultural paradigms);
- teach techniques for increasing cultural self-assessment and awareness; and
- offer opportunities for role playing and feedback.

After such training, meetings should regularly be held during which staff can raise questions, discuss problems and receive feedback. Parents and other resource persons from the communities should take part in these events, regularly and/or to discuss specific topics.

A multicultural resource library (which also includes general informational materials about families and disabilities, family/professional partnerships, and so forth) can be helpful to personnel, parents and other family members, and members of the community at large. Where such a resource is developed, staff, family and other community members should be made aware of its availability. Access should be as convenient as possible.

Training for family and community members in their communities would enhance mutual understanding between families and professionals, and effective service provision as well. Sessions might explore differences in perspective which community members may encounter in working with administrative or service personnel, and ways in which they can deal with cultural ignorance or insensitivity.

State agencies and early intervention programs serving infants, toddlers and their families should look at the organizational information collected in their surveys and determine their needs for active outreach to find and involve members of cultures represented in the state at all levels of staffing. Hiring and promotion policies should clearly state that recruitment and promotion of members of the state's cultural communities is a priority at all levels (But, members of particular cultures should not be hired with the notion that they will solely serve members of their own cultures.) The resulting diversity will not only enrich the programs affected, but will enhance state and provider credibility vis-a-vis traditionally under- or unserved populations.

Well-trained interpreters (paid, volunteer, or both) should be available for speakers of all languages in the state (including all sign languages), so that no client family or potential client family will be without services or access to administrative or program personnel at any time due to a language barrier.

Monitoring and Evaluation

The effectiveness and sensitivity of all resources to which clients are connected should be carefully and thoroughly monitored by outside professionals trained in cultural diversity issues as well as in early intervention and may require the services of a well-trained interpreter as well. Monitoring reassures clients of the ongoing interest and concern of program administrators, and helps to ensure that client families are not lost to the system due to inadequate or insensitive service provision.

Process evaluations of individual family programs should be carried out on a regular and ongoing basis to ensure that a program is addressing all of a family's

needs, including specific cultural needs. This helps to ensure that necessary modifications can occur promptly—before a family begins to feel isolated or alienated from the program.

Formal and informal evaluations by families served should be solicited (anonymously if so desired by families) and utilized as part of ongoing program evaluation.

Guidelines for Addressing Cultural Diversity Issues in the Context of P.L. 99-457

State policymakers may initially want to appoint a task force or committee of the Interagency Coordinating Council or other body to begin to explore some of the issues and suggestions outlined in this document, as well as additional state-specific issues which will arise. Following are some very broad questions which such a group may find useful to address in beginning to grapple with the definition, development, implementation, and evaluation of a statewide, state-specific, culturally sensitive service delivery program for infants and toddlers with disabilities and their families.

1. How will we reach an agreed-upon definition of cultural sensitivity (and what a "culture" is), as well as agreement about what we anticipate may be the kinds of cultural issues or tendencies with which we should become familiar?
2. Given that developing and implementing a culturally sensitive program may take a considerable commitment of funds, what sources—federal, state and local; public and private—can we begin to explore and tap into for this purpose?
3. How can we best carry out an assessment of the state population—demographic and ethnographic—and begin to establish liaisons within the state's cultural communities? What data and mechanisms already exist which may be useful in this regard?
4. How can cultural sensitivity training for students, service providers, and state agency personnel most efficiently and effectively be developed and integrated into current staffing and educational requirements?
5. How will we attract and retain paid personnel and volunteers from the cultures represented in our state to positions at all levels of the planning, administration, implementation, and evaluation process?

With these kinds of issues explored and addressed, state personnel should be in a position actively and quickly to begin to move toward establishing programs to meet the needs of all infants and toddlers with disabilities and their families in the state.

The effectiveness of programs to provide services for multicultural populations of infants and toddlers with disabilities and their families rests heavily upon the sensitivity, understanding, and respect paid to the specific cultural, familial, and individual diversity involved. Thus, if comprehensive family-centered community-based early intervention for all infants and toddlers with disabilities is to be achieved, cultural awareness and sensitivity must be stated as a priority at the outset. Good intentions alone will not achieve culturally appropriate services for culturally diverse young children with disabilities and their families; commitment, creativity, openness to new ideas, and resources are needed to make such a vision a reality.

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Resource Programs

Projects and Organizations Which Include and/or Affect Culturally/Linguistically Diverse Infants and Toddlers and Their Families

Following are some of the resources which have come to our attention in the course of preparing this publication. Staff of each have expressed willingness to appear as a resource and completed a questionnaire which provided the information that follows. The list is by no means exhaustive, but does cover a range of programs and services, not all of which work specifically with young children with disabilities. The list is divided into "organizations," which are permanent entities with some relationship with multicultural populations, and "projects," which are funded for specific activities for specific time periods. Within these two categories, programs are listed alphabetically within states. Further breakdowns would be misleading in some cases. The reader looking for resources is advised to peruse the diversity of the entire list.

Organizations

CALIFORNIA

California Urban Indian Health Council, Inc.
2422 Arden Way, Suite A-32
Sacramento, California 95825
(916) 920-0313

The Council is a non-profit Indian managed corporation established to provide a unified voice to articulate the health needs of the state's growing urban Indian population. The Council provides support to local urban and rural Indian health projects, services of which include: dental care; optometric care and eyeglasses; prenatal care and WIC; child immunizations; health education programs; family planning; venereal disease screening; well-baby clinics; and transportation to and from other services. Specific projects include:

- *Indian Perinatal Access Project*
Rosanna Jackson, Project Director
- *Fetal Alcohol Syndrome Prevention Project*
Joseph Roche, Project Director
- *An American Indian Comprehensive Maternal and Child Health Program*
Karen Tracy, Project Director.

Hispanic Family Institute
An Adoption/Foster Family Agency
A Division of El Centro Human Services Corporation
5701 S. Eastern Avenue
City of Commerce, California 90040

To recruit appropriate prospective Latino adoptive parents and/or foster homes and subsequently, to provide the necessary comprehensive services, including home assessments and placement of children in adoption and foster care and all follow-up services which may be necessary, including post-adoption services.

North East Medical Services
1520 Stockton Street
San Francisco, California 94133
(415) 391-9686
Sophie H. Wong, Executive Director

Provide bilingual and culturally sensitive health care to monolingual Chinese and Vietnamese populations. A comprehensive perinatal program and pediatric care onsite program has been established for financially burdened families.

Northern California Comprehensive Sickle Cell Center
San Francisco General Hospital
Pediatric Hematology and Adult Hematology Services
1001 Potrero Avenue, Room 6J5
San Francisco, California 94110
(415) 821-5169
Dr. William Mentzer, Pediatric Hematology
Dr. Stephen Embury, Adult Hematology
Mary Roulan, PNP, Pediatric Hematology

The population served by the organization includes any person at risk of having a child with hemaglobinopathy, any person wishing testing, and any person diagnosed with hemaglobinopathy, including sickle cell disease, thalassemia and other blood conditions. The program includes patient care, screening, community education, counseling, research, advocacy and psychosocial support. The Center consists of interdisciplinary teams including physicians, psychologists, nurses, social workers, and genetic counselors. Effective November, 1989, the Center will be part of a California State Newborn Screening Program.

Santa Clara County Health Department
Refugee Health Services Program
Park Alameda Health Facility
976 Lenzen Avenue
San Jose, California 95126
(408) 299-6970
James Powell, Program Manager

The program provides a variety of preventive health care services for all county refugees, regardless of financial status. Staff language capabilities include English, Cambodian, Chinese, Cantonese, Fukienese, Mandarin, Farsi, French, Laotian, Thai and Vietnamese.

T.H.E. Clinic for Women, Inc.
Asian Health Project
3860 West King Boulevard
Los Angeles, California 90008
(213) 295-6571
Kazue Shibata, Director, Asian Health Project

T.H.E. Clinic is a non-profit community clinic specializing in gynecological and obstetrical services. The Clinic provides health education and interpretation services to culturally diverse populations in Los Angeles County and Asian Pacific communities with emphasis in family planning and productive health. Resource materials are available in English, Japanese, Vietnamese, Cambodian, Lao, Tagalog, and Thai.

COLORADO

BUENO Center for Multicultural Education
Education Building, Campus Box 249
University of Colorado at Boulder
Boulder, Colorado 80309-0249
(303) 492-5416
Dr. Leonard Baca, Director

The Center promotes quality education with an emphasis on the value of cultural pluralism in our schools through a comprehensive range of research, training and service projects. The Center is committed to facilitating equal educational opportunities for cultural and language minority students. Programs include a Bilingual/Multicultural/Special Education Resource Center, Bilingual Special Education Curriculum Training, Bilingual Special Education Inservice Training, Paraprofessional Training Project, High School Equivalency Program, and Family English Literacy Program.

DISTRICT OF COLUMBIA

National Coalition of Hispanic Health and Human Services Organizations (COSSMHO)
1030 15th Street, N.W., Suite 1053
Washington, D.C. 20005
(202) 371-2100
Mary Thorngren, Director, Provider Education
Raphael Metzger, Publications

COSSMHO's priorities include mental health, chronic disease prevention, health promotion, substance abuse, maternal and child health, youth issues and access to health services. COSSMHO conducts national demonstration programs, coordinates research, and serves as a source of information, technical assistance and policy analysis. A number of publications are available, including *Delivering Preventive Health Care to Hispanics: A Manual for Providers, Hispanic Families, and H.O.T.—The Hispanic Outreach Team.*

MASSACHUSETTS

Massachusetts Developmental Disabilities Council
Commonwealth of Massachusetts
600 Washington Street, Room 670
Boston, Massachusetts 02111
(617) 727-6374
Jo Bower, Associate Planner

Publication, *Minorities with Disabilities in Massachusetts: Service Needs and Program Initiatives.* The Council has developed disability information and referral sheets for languages spoken in the state. Council has a committee that meets monthly to implement projects related to minorities and disabilities.

MICHIGAN

Ann Arbor Public Schools
Special Education Department—Pupil Personnel Services
2555 S. State Street
Ann Arbor, Michigan 48104
(1) (313) 994-2318
Margery Haite, Teacher/Consultant

Provide special education services to birth to 5 year olds identified under P.L. 99-142. Services include special education teacher, speech and language teacher, physical therapist or occupational therapist as needed.

MINNESOTA

PACER Center, Inc. (Parent Advocacy Coalition for Educational Rights)
4826 Chicago Avenue, South
Minneapolis, Minnesota 55417
(612) 827-2966
Maria Anderson, Early Childhood Coordinator
Virginia Richardson, Parent Training Manager
PACER serves parents of children and young persons with all disabilities—physical, mental, learning and emotional. The Center has a special emphasis on reaching underrepresented populations, and translates workshop flyers, provides interpreters, and holds workshops in the community. Some educational materials are available in Spanish and Hmong. The Center also has an Early Childhood Family Training Project.

MISSISSIPPI

Mississippi State Department of Health Genetic Screening Program
P.O. Box 1700
2423 North State Street
Jackson, Mississippi 39215-1700
(601) 960-7619
Daniel R. Bender, Director, Genetic Screening

Testing, screening, and followup of all persons, including all newborns, with genetic disorders in the state.

NEW MEXICO

Southwest Communication Resources, Inc.
P.O. Box 788
Bernalillo, New Mexico 87004
(505) 867-3396
Randi Suzanne Malach, Project Director

A non-profit community based organization dedicated to providing specialized services to families who have children with special needs. These services include:

- *Pueblo Infant Parent Education (PIPE) Project*
A home-based infant-family early intervention program for families with infants and toddlers who have health impairments, developmental disabilities, or who are at "risk" of having a developmental disability. Services include parent support and training, and therapeutic child development.
- *Family Services Program*
A home-based family preservation program for families whose children are "high risk" for abuse or neglect. Services include parent training and support.
- *Education for Parents of Indian Children with Special Needs (EPICS) Project*
A statewide community-based parent training and information program for American Indian families whose children have chronic health impairments and handicapping conditions. Services include parent training and support, and consultation for professionals serving American Indian children with special needs.

NEW YORK

New York Council on Adoptable Children
666 Broadway, Suite 820
New York, New York 10012
(212) 475-0222
Ernesto Loperena, Executive Director
Recruitment, preparation and referral of prospective adoptive parents for older, handicapped and minority children.

New York State Genetic Services Program
New York State Department of Health
Wadsworth Center for Labs and Research
Empire State Plaza, Room E275
P.O. Box 509
Albany, New York 12201
(518) 473-9830
Karen Greendale, M.A., Genetic Services Program Coordinator
Program serves children and adults with birth defects or genetic conditions; anyone with questions about risk for birth defects or genetic disease due to family history, drug or medical exposure, ethnic background, etc. Twenty-three genetic counseling programs are administered throughout the state of New York. Although all of them see culturally diverse patient populations, some target specific ethnic groups such as Chinese, Chasidim, Hispanics, Blacks, etc., at risk for specific genetic conditions.

TENNESSEE

Tennessee Newborn Hemaglobinopathy Screening Program
Tennessee Department of Health and Environment
Maternal and Child Health
525 Cordell Hull Building
Nashville, Tennessee 37219
(615) 741-7335
Suzanne Rothacker, R.N., Ph.D., Nurse Consultant
All newborn infants born in Tennessee hospitals are served. The goals of this program are to reduce infant mortality and morbidity due to sickle cell disease and other hemoglobinopathies through early diagnosis and initiation of prophylactic penicillin treatment and comprehensive medical care, to identify families at risk, and to reduce duplication in sickle cell screening.

TEXAS

CEDEN Family Resource Center for Development, Education and Nutrition
1208 East Seventh Street
Austin, Texas 78702
(512) 477-9017
Emily Vargas Adams, Ph.D., Executive Director
Provides educational and human services to meet the needs of children and parents of all ethnic backgrounds, with special emphasis upon Hispanic and African American families. This resource and development center also produces bilingual educational materials and media and provides advisory services throughout the U.S. for organizations addressing the special needs of culturally diverse populations. CEDEN's Parent-Child Program for reversing and preventing developmental delays in high-risk children has been replicated in communities of East and South Texas. CEDEN's materials are for home parent educators, classes and parents.

VIRGINIA

Interstate Research Associates
7926 Jones Branch Drive, Suite 1100
McLean, Virginia 22102
(703) 893-6778
Ray Workman
The organization serves mobile migrants served in migrant Head Start programs throughout the United States (24 grantees in approximately 33 states). IRA is the resource center providing training and technical assistance (information; resources; materials; national, regional, and on-site training, etc.) to the 24 migrant Head Start grantees in 33 states in the U.S. IRA has served in this capacity as a training and technical assistance provider for approximately 20 years.

Mental Health Services for Migrant Families
East Coast Migrant Head Start Project
4200 Wilson Boulevard, Suite 740
Arlington, Virginia 22203
(703) 243-7522
To serve migrant families and children who travel along the Eastern U.S. seeking agricultural work. These families have stresses unique to living conditions which adversely affect the mental health of the child. The project will provide comprehensive mental health services to approximately 60 children and their families. The project will also educate local mental health workers about the unique characteristics of migrant children and their families; educate ECMHSP staff in the recognition of mental health services and their use; and train ECMHSP center staff as a functioning support system and linkage to the provision of mental health services.

WASHINGTON

International District Community Health Center
416 Maynard Avenue South
Seattle, Washington 98104
(206) 461-3235
Bria Chakofsky, Clinic Manager
The center provides multilingual, culturally sensitive primary health care to Asian/Pacific Islanders, aged prenatal to elderly, regardless of ability to pay. The Center has a staff that speaks twelve Asian and Pacific Islander languages and dialects (Khmer, Cantonese, Toisanese, Mandarin, Hmong, Mien, Lao, Korean, Tagalog, Ilocano, Thai and Vietnamese).

Novela Health Foundation
2524 16th Avenue South
Seattle, Washington 98144
(206) 325-9897
Sabrina Souffront, Administrative Assistant
Serving the Hispanic and English communities, the foundation consists of a group of health professionals developing appropriate health educational materials. Since 1986, the foundation has published health videos—*Face to Face* and *The Awakening of Raymond*, as well as a publication on *Caring for the Latino AIDS Patient—HIV Test Counseling*. Food charts are currently being developed.

Projects

ARIZONA

Community-Based Genetic Services Network for Southwestern Native Americans
University of Arizona College of Medicine
Department of Pediatrics
Tucson, Arizona 85724
(602) 795-5675
H. Eugene Hoyme, M.D., Project Director
To address the low utilization of genetic services and the presumably increased frequency of congenital anomalies and genetic disorders in Native Americans of the Southwest due to alcohol abuse and high rate of diabetes. The project addresses this low utilization through a community-based network of birth defects/genetics clinics, health professional education, and community education, taking into account the cultural and language variability of Native Americans by using existing local public health and social service resources.

Community Systems Approach to American Indian Families
Institute for Human Development
Northern Arizona University
Box 5630
Flagstaff, Arizona 86011
(602) 523-4791
Richard Carroll and Joanne O'Connell, Co-Directors
Provide culturally appropriate intervention services to high risk Native American infants, their families and the community through the use of indigenous paraprofessionals as service providers and trainers. Have also developed publications, family service plans, protocols, assessment procedures and other related materials.

Native American Research and Training Center
University of Arizona
1641 East Helen Street
Tucson, Arizona 85729
(602) 621-5075
Jennie R. Joe, Ph.D., MPH, Director
Paul Skinner, Ph.D., Co-Director
Research and training activities directed toward improving the quality of life for American Indians and Alaska Natives with disabilities. Projects include research into sociocultural aspects of disability and rehabilitation, development of culturally relevant service delivery models, and/or training activities related to needs and problems of Native Americans with disabilities.

CALIFORNIA

Child Welfare Social Work Traineeships to Encourage Participation of Working and Minority Students in Child Welfare Practice
California State University, Long Beach Foundation
Department of Social Work
1250 Bellflower Boulevard
Long Beach, California 90840
(213) 985-8180
Janet Black, LCSW
A child welfare traineeship for MSW students in collaboration with Orange County Social Service Agency, to meet the multiple demands of abused and neglected children who require professionally trained chidlren's service workers. The MSW program focuses on cultural diversity and offers a part-time program. Project focusses on providing stipended field work placements at Orange County Social Services Agency to MSW students in the area of child welfare with particular emphasis on working students and on minority students. The project hopes to attract minority students to child welfare practice.

County Hospital Genetic Counseling Service for High-Risk, Underserved, Multiethnic, Monolingual Perinatal Population
University of California at San Francisco
Department of Obstetrics/Gynecology and Reproductive Sciences
San Francisco, California 94143
(415) 821-3133
Ilana Mittman, Project Director
A model access program for bringing sophisticated genetic counseling, education and prenatal diagnosis to an underserved, high-risk population at San Francisco General Hospital Medical Facility.

Infant Mortality Among Indochinese Refugees
International Population Center
San Diego State University
San Diego, California 92182-0383
(619) 594-2874

John R. Weeks, Ph.D., Project Director
(ended 2/25/88)
Used two new sources of data to estimate the level of infant mortality among Indochinese refugees, to compare those levels with other population groups, and to develop Indochinese-specific risk profiles for use by health care professionals, planners, and policymakers.

Southeast Asian Developmental Disabilities Prevention Program (SEADD)
1031 25th Street
San Diego, California 92102
(619) 235-4270
Dorothy M. Yonemitsu, LCSW, Program Director
James O. Cleveland, Ed.D., Project Manager
Serve Southeast Asian refugee children from 0-3 and their families. Are developing a "Bicultural Bilingual Counselors Training Manual." Videotapes on the postnatal care of infants and their mothers are available in English, Cambodian, Hmong, Laotian, and Vietnamese.

CONNECTICUT

Ninos Especiales Project
Division of Child and Family Studies
University of Connecticut Health Center
Pediatric Department
The Exchange, Suite 164
270 Farmington Avenue
Farmington, Connecticut 06032
(203) 674-1485
This model demonstration project provides culturally sensitive, family-focussed early intervention services to Puerto Rican children, birth through 3, who have severe multiple handicaps. Training is available to early intervention programs currently serving the Puerto Rican population.

DISTRICT OF COLUMBIA

Child Welfare Traineeship
Howard University
School of Social Work
6th and Howard Place, N.W.
Washington, D.C. 20059
(202) 636-7300
Clarice Walker
To provide financial assistance through traineeships for full-time degree students in Howard's School of Social Work Masters Degree program to receive specialized training in child welfare. A special concern is to increase the number of Black professional social workers with child welfare expertise and to improve the child welfare delivery systems in direct services and management.

Gallaudet University
800 Florida Avenue, N.E.
Washington, D.C. 20002
- *Interaction and Support—Mothers and Deaf Infants*

(Gallaudet Research Institute, Kendall School—PAS 9)
(202) 651-5206
Kathryn Meadow-Orlans, Ph.D., Project Director
This project is designed to investigate the impact of deafness on interaction of deaf infants and their hearing mothers. Data are being collected at ages 9, 12, 15, and 18 months, including videotapes of face-to-face interaction, mastery motivation with toys, free play, attachment, plus interviews and questionnaires to elicit information about family stress and available support systems.
- *Interaction and Support—Mothers and Deaf Infants*

(Gallaudet Research Institute, Kendall Demonstration Elementary School)
Data identical to that noted above will be collected from deaf families with both deaf and hearing children. The Kendall Elementary School has programs for deaf infants and preschoolers as well as for older children.
- *National Information Center on Deafness*

(202) 651-5051
Loraine DiPietro, Director

Linkages
c/o TCI, Inc.
3410 Garfield Street, N.W.
Washington, D.C. 20007
Nancy Gale, Editor
TCI, Inc., is an Indian-owned small business that publishes *Linkages*, a bi-monthly newsletter that covers topics pertaining to Indian child welfare.

GEORGIA

Reduction of Minority Infant Mortality in Georgia
Georgia CONTINUUM Alliance for Healthy Mothers and Children
1252 West Peachtree Street, N.W.
Suite 311
Atlanta, Georgia, 30309
(404) 873-1993
W. Mary Langley, RN, MPH, Project Director
Reduce racial/ethnic disparities in rates of infant mortality in Georgia by reducing postneonatal mortality rates associated with inadequate parenting skills and poor utilization of prenatal and child health care services and establish self-sustaining coalitions that will monitor and address problems that contribute to poor pregnancy outcomes. The Minority Connection Project has developed programs through the Black church to reach at-risk populations for high infant mortality rates and teenage pregnancy.

HAWAII

Health Start Program for Promotion of Positive Child Development and Prevention of Child Abuse
Hawaii Family Stress Center
Kapiolani Medical Center
2910 Kapiolani Boulevard
Honolulu, Hawaii 96826
(808) 732-0000

Gail Breakey, RN, MPH, Project Director
Community-based family support program serving children aged 0-5 from underserved, culturally diverse populations. Goals are to prevent child abuse and neglect, to promote positive child development to *all* at-risk families of newborns in geographically based target areas. Families receive home visiting services until target child reaches age 5.

Infant Feeding and Growth—U.S.-Related Pacific Islands
University of Hawaii
Honolulu, Hawaii 96822
(808) 948-8832
Gigliola Bruffi, M.D., Project Director
To offer a continuing education program on human lactation, infant feeding and growth monitoring to health personnel in U.S.-related Pacific Islands as part of a broad effort to increase breastfeeding incidence and duration and monitor infant and child growth.

Preschool Preparation and Transition Model
Department of Special Education
University of Hawaii
208 Wist Hall
1776 University Avenue
Honolulu, Hawaii 96822
(808) 948-7740
Valerie Campbell
(project is ending)
Developing service delivery model to prepare handicapped infants, families, professionals for least restrictive preschool environments. Many participants come from minority ethnic groups.

ILLINOIS

Illinois Project for Statewide Screening and Follow-Up of Newborns for Hemoglobinopathies
Illinois Department of Public Health, Genetic Diseases Program
535 West Jefferson
Springfield, Illinois 62761
(217) 782-6495
Marla J. Buro, B.A., Sickle Cell Program Coordinator
This project has expanded the newborn screening component of Illinois Department of Public Health, Genetic Diseases Program, to include screening and follow-up of all newborns in the state for sickle cell disease/trait and other hemoglobinopathies. The project provides ongoing diagnostic services, medical consultation, prophylactic medication for infants with sickle cell disease, and confirmatory testing and diagnosis for infants who are presumptive for sickle cell traits. Education/counseling services for parents of infants identified with sickle cell trait are also available. Finally, it is the intent of this project to provide ongoing education and information about sickle cell disease/trait and other hemoglobinopathies to health care professionals and the public.

KANSAS

Adoption for Black Children
Lutheran Social Service of Kansas
1855 North Hillside
Wichita, Kansas 67214
(316) 686-6645
To provide families for Black children who would otherwise remain in foster care and specific training for social workers in working with Black clients.

NEW JERSEY

Project to Increase the Utilization of Genetic Testing and Counseling Services by Hispanic and Immigrant Populations
New Jersey State Department of Health
Special Child Health Services
CN364
Trenton, New Jersey 08625
(609) 292-1582
Doris Kramer
(ended 6/30/89)
To develop and test strategies to increase utilization of genetics services by Hispanic and immigrant populations in five counties in the northeastern region of the state. As a component of the overall goal, the project sought to assist genetics service providers to communicate more effectively with their non-English speaking clients and to provide culturally sensitive services.

NEW MEXICO

CHEWS (Children with Handicaps, Expanding Statewide Services) Nutrition Project
New Mexico Health and Environment Department
Public Health Division
Maternal and Child Health and Nutrition Bureaus
Harold Runnels Building, Room N—3078
Santa Fe, New Mexico 87503
Ann Taulbee, Project Director
Cary Bujold, RD, Project Coordinator
The project's primary concern is access to care for children with special health care needs and insuring that they receive the highest quality of nutrition services available. Project staff have created a system throughout New Mexico to meet this need, have trained providers to conduct nutrition screening, and have identified local community-based dieticians for the provision of services. They are presently working toward identifying reimbursement methods for the community-based nutrition services. Professional, paraprofessional and parent nutrition education materials have been developed. All parent education materials are bilingual (English-Spanish), with one handout—"Feeding Positions"—available also in Navajo.

Project Ta-kos
Alta Mira Specialized Family Services, Inc.
3201 4th Street, N.W.
Albuquerque, New Mexico 87107
(505) 345-6889
Understanding Family Uniqueness Through Cultural Diversity: a 12-hour course developed by Project Ta-kos to assist professionals working with families who have children with developmental delays, or are considered "at risk," to view the dynamics of culture when an interventionist works with families. In order to avoid stereotypical lists of assumptive characteristics by ethnicity, the course uses the theory that suggests that cultural sensitivity is a developmental process whereby the "supportive" interventionist passes through the following stages: awareness of ones' own culture; consideration of the existence of diversity; heightened awareness of cultural aspects; and the final stage of reaching and maintaining a balance or integration. Once an awareness of the need for cultural responsiveness has been established the course explores diversity regarding common variables known as "world views" or "life ways" and discusses ways to learn procedures and techniques for gathering information about a family's unique personal views and preferred lifestyle while minimizing the interventionist's intrusiveness. The final part of the course helps the interventionist consider which variables are most relevant to the provider/family partnership.

NEW YORK

CROSSROADS: A Cooperative Transagency Program for Preschool Culturally/Linguistically Diverse Exceptional Children
875 Elmwood
Buffalo, New York 14222
(716) 886-5857
Isaura Barrera Metz, Director
Coordinate and deliver services to culturally/linguistically diverse (including Hispanic, Black, Asian American and American Indian) preschool handicapped and at risk children, 0-5, and their families in the least restrictive settings; prepare program staff and other caregivers to serve these populations. Services are integrated into existing programs rather than being segregated separate services.

Determinants of Adverse Outcome Among Toddlers of Adolescent Mothers
Research Foundation for Mental Hygiene
New York Psychiatric Institute
New York, New York 10032
(212) 460-2298
Gail Wasserman, Ph.D., Project Director
To follow longitudinally 100 Black and Hispanic adolescent mothers and their young children and to compare child outcome to a group of matched older women and children. Investigate environmental factors involved in child outcome and examine role of the caregivers, especially grandmothers, as they affect children's outcomes.

Identification, Intervention, Involvement: Training Personnel Working with Migrant Parents of Infants and Toddlers
State University College
Old Main Building, 113D
Department of Education Studies, SUNY
New Paltz, New York 12561
(914) 257-2830 or 2838
Lynn Sarda, Project Coordinator
Project serves personnel working with migrant families—educators, social service and health workers, parents, day care staff, administrators, case managers, and early interventionists. Three one-half day sessions that include videos, professional and parent materials, and activities following training manual guidelines are provided. These multicultural materials aid families in the identification of special needs, intervention and play activities, and rights and entitlements.

NORTH CAROLINA

University of North Carolina
Department of Maternal and Child Health
School of Public Health
Campus Box 7400
Chapel Hill, North Carolina 27599
(919) 966-5974
Elizabeth Walkins, D.Sc., Project Director
- *Migrant Lay Health Advisors—A Strategy for Health Promotion*

Migrant farmworker women and children are predominantly from minority ethnic groups. The project seeks to reduce the proportion of migrant women delivering low birth weight infants; reduce incidence of serious and/or chronic conditions among migrant newborns and infants; increase prenatal visits to a minimum of 9 during pregnancy and one postpartum visit; and increase well-child visits to 5 for children under one.
- *Improving the Health of Migrant Mothers and Children*

(ended 9/30/88)
The goal of the project was to improve the health and nutritional status of migrant farmworker women and children from 0-5 receiving health services at the Tri-County Community Health Center, a federally funded health center. In 1986, the prenatal population served was 62% Hispanic, 24% Black American, 12% White American, 1% Haitian and other.

OKLAHOMA

Oklahoma State Department of Health
Maternal and Child Health
P.O. Box 53551
Oklahoma City, Oklahoma 73152
- *Oklahoma Native American Genetic Services Program*

(405) 271-6617
Mary Ann Coffman, M.S., Project Director
Provides a coordinated network of genetic services that are culturally acceptable and financially accessible to Native Americans in Oklahoma.

• *Family Support Project*
(405) 271-4471
Nancy Fire, R.N., M.S., Project Director
To assess the needs of the urban Oklahoma City Southeast Asian families who have children with special health care problems. To develop family support projects with four Native American tribal groups.

SOUTH CAROLINA

South Carolina Department of Health and Environmental Control
Division of Children's Health
2600 Bull Street
Columbia, South Carolina 29201
• *Follow-up of Identified Newborns with Hemoglobinopathies*
(803) 737-4050
Rose W. Alford, Newborn Screening Program Administrator
Infants receive tests for PKU, congenital hypothyroidism, and hemoglobinopathies (mainly sickle cell disease) as part of the neonatal screening mandated by state law. Follow up is provided for those found with positive results for treatment and medical management. The Hemoglobinopathy Project targets those infants found with traits and disease. Infants with traits are referred to the Regional Sickle Cell Foundations, so their parents can receive genetic information and testing. Those infants with sickle cell disease are referred for long-term medical services, including prophylactic antibiotics, and are tracked for the first three years of life to assure appropriate medical services.
• *Statewide Action Plan to Promote Breastfeeding*
(803) 734-4610
Robert H. Buchanan, Jr., Project Director
A project to increase the number of low income and Black mothers who breastfeed. Breastfeeding promotes maternal infant bonding which is particularly important to families with infants with disabilities. Further, certain disabilities may call for specific instruction and techniques with regard to breastfeeding, which the project can provide.

SOUTH DAKOTA

Mental Health Treatment Continuum for Abused and Neglected Children and Their Families
South Dakota Department of Human Services
Division of Mental Health
700 Governors Drive
Pierre, South Dakota 57501
(605) 773-5991
A local demonstration project to develop a comprehensive system of care for youth and families served by the child welfare system by combining resources and personnel of Child Protection Services and private mental health centers. The project will prevent unnecessary removal of children from their families and wil provide an alternative to residential treatment or hospitalization for children served by CPS. The project will serve a large percentage of Native Americans.

TENNESSEE

Tennesee Breastfeeding Promotion Project
Tennessee Department of Health and Environment
100 Ninth Avenue North
Nashville, Tennessee 37219-5405
(615) 741-0265
Minda Lazarov, MS, RD, Project Director
To increase the rate and duration of breastfeeding among low income women in two rural counties and one urban county with large Black populations.

TEXAS

Acculturation, Psychosocial Predictors and Breastfeeding
University of Texas Medical Branch
Department of Pediatrics
Route C-51
Galveston, TX 77550-2774
(409) 761-1139
David K. Rassin, Principal Investigator
A research project designed to increase incidence and maintenance of breastfeeding in a U.S.-Mexico border population. The population will be characterized by demographic factors with respect to ethnic background and degree of acculturation (from Hispanic to Anglo and from Anglo to Hispanic).

U.S.-Mexico Border Health Association/Carnegie-Pew-PAHO
6006 N. Mesa
Suite 600
El Paso, Texas 79912
(915) 581-6645
Dr. Herbert H. Ortega, Project Director
• *Maternal and Infant Risk Assessment Referral Training Project* (U.S.-Mexico Border Health Association)
(ended 3/31/89)
To improve health status of women and infants on Texas-Mexico border by 1) maximizing utilization of health resources and improving coordination of services in both nations; 2) enhancing binational staff development efforts; 3) increasing coordination of Maternal and Child Health services between the U.S.-Mexico Border Health Association and the Texas Department of Health.
• *Primary Health and MCH Technologies for Women, Adolescents and Children* (Carnegie-Pew-PAHO)
To develop and establish binational institutional networks for an inter-disciplinary investigation collaboration, education and training along the U.S.-Mexico border, with the purpose of improving women's health and health of adolescents and children.

UTAH

The Navajo Way
Southeastern Utah Community Action Program
P.O. Box 508
Wellington, Utah 84542
(801) 637-4960
Lynnette M. Hadden, Executive Director
Development of preschool materials on, including a videotape about, Navajo culture.

VIRGINIA

Hampton University Mainstreaming Outreach Services
Hampton, Virginia 23668
(804) 727-5751 or 5533
Marie S. Shelton, Director
To help schools, community agencies and other organizations develop programs to integrate handicapped children 0-8 from diverse cultural backgrounds into regular classrooms and community programs.

WASHINGTON

Khmer Cultural Enrichment Project
City of Seattle Head Start Program
105 Union Street, Suite 160
Seattle, Washington, 98101
(206) 386-1021
John Wrobleski, Education Specialist
The project will develop staff and parent training materials and classroom activities and materials on the Khmer of Cambodia. The project will also demonstrate the process of sensitively gathering information from non-English speaking and limited-English speaking families.

Recommended Reading

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